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ABSTRACT

This collection of articles on the Sudden Infant Death Syndrome (SIDS), drawn from a southeastern regional symposium on the subject, summarizes much of what is known about the occurrence of SIDS, including current information about its causes. The background of state action in Florida is reviewed, with emphasis on the need for increased public and professional awareness of SIDS and the heavy burden of grief and guilt experienced by families involved. Medical background is presented in an article describing the incidence of the disease (also known as "crib death") and characteristics of victims and possible causes. A transcript of an SIDS parents' panel relates experiences of parents and hospital personnel, emphasizing the significance of insisting on autopsy in determining the cause of death. Another article describes the grief counseling program of the North Carolina SIDS Project, which provides counseling services in conjunction with the collection of data on various aspects of SIDS, including bereavement behavior of families. A discussion of the medical examiner's general role and relationship with SIDS parent groups focuses on the distinction between medical and legal aspects. A discussion of the role of public health agencies in SIDS case management defines three areas of responsibility: parent support, public awareness and improved reporting. And a final article, on the role of first contact personnel in SIDS case management, deals with the functions of law enforcement officers, hospital emergency room staff and other personnel. (Author/BF)

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Cover Illustration

Roman Lopez, three-month-old son of Mr. and Mrs. Cecil Lopez, Tallahassee.

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SIDS—The Florida Perspective

EMILY H. GATES, M.D.
JACKSONVILLE

Very often the element of disbelief surrounds death—the idea that surely it is not real, that tomorrow everything will be all right again. This is never more apparent than when a baby dies, particularly when the baby dies of the Sudden Infant Death Syndrome (SIDS), otherwise known as "crib death."

Deaths due to SIDS have been occurring throughout the world since biblical times, but the unfortunate fact remains that today when such deaths occur all too often parents have never heard of SIDS. This is likely to be true for neighbors, friends and relatives, even to law enforcement and emergency medical personnel who usually are the parents' first outside contact after they find their infant apparently dead in its bed.

The parents, themselves, are probably young and in most instances have never encountered death in a family member or close friend. Now their own baby, which they put down to sleep a few hours earlier in apparent good health, is suddenly dead. Buy why? And how?

This issue of Florida's Health is devoted to unraveling part of that mystery. On the following pages are summarized much of what is known about the occurrence of SIDS, including the best current information about its causes.

Let us look first at the situation in Florida where in 1974 there were 109,781 recorded live births and 1,903 recorded infant deaths. Most of those (1,387) typically occurred in the neonatal period (first 28 days) because of conditions such as premature birth, its complica-

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Dr. Gates is Codirector of the Sudden Infant Death Syndrome Project in Florida and also Administrator of the Child Health Section, Health Program Office, Department of Health and Rehabilitative Services, State of Florida.

tions, and congenital defects. However, the Sudden Infant Death Syndrome accounted for 152 infant deaths, practically all in the postneonatal period (28 days to one year), or 1/12 of all infant deaths and 1/3 of all occurring after the neonatal period.

This figure has been rising since 1968 due to improved reporting rather than an actual increase in occurrence. In 1968 the Health Program Office (then State Board of Health) made known its interest in the SIDS problem by this letter circulated from the Bureaus of Maternal and Child Health and Vital Statistics to physicians throughout the state.

" 'SUDI' may be defined as death occurring suddenly and unexpectedly in an infant who was not known to be ill, or following a brief mild illness not expected to result in death. Although occasionally an explanation is found at autopsy, in many cases the pathology found, if any, does not adequately explain the fatal outcome. Henceforth, in Florida, the term 'SUDI' will be accepted on Death Certificates as the cause of death, provided suspected contributory causes, if found clinically or at autopsy, are also supplied. Only in this way can we hope to determine the significance of this entity as a cause of infant death in Florida."

It was not until 1974 that "SIDS" was assigned a code number and included among the other conditions nationally accepted as a cause of death. But Florida's action produced the desired improvement in SIDS reporting in this state. The number of identified cases of sudden unexplained infant deaths rose from 41 in 1968 to 96 the following year and continued a gradual increase thereafter. A second spurt coincided with a late 1973 visit to Florida by a representative of the National Foundation of the Sudden Infant Death Syndrome (now National Sudden Infant Death Syndrome Foundation).

Statistics gained in recent special studies elsewhere indicate a SIDS incidence of around 2.8 per 1,000 live births. On that basis it is estimated that Florida may have as many as 300 SIDS deaths annually. The discrepancy between this figure and present reporting may simply indicate that many deaths due to SIDS are still unrecognized or are inadequately recognized on Florida death certificates, or it may indirectly reflect a lower rate of SIDS occurrence in Florida, due to such depressant factors as climate. Only continued careful study can give the answer to such questions.

Passage of the 1970 Medical Examiner's Act in Florida, creation of the Medical Examiner's Commission and appointment of District Medical Examiners, provided the next opportunity for better management of SIDS cases and further improvement in reporting. By 1974 communication was well established between the Medical Examiners, and staff of the Bureau of Adult Health and Chronic Diseases, and

Child Health Section, both of the Division of Health. SIDS was included as a major subject at the "Law Enforcement and Medicine Conference" in October 1974 and was discussed again at the Third Annual Medical Examiners' Conference in October 1975. These Conferences were sponsored by the Florida Medical Examiner's Commission and the Division of Health, Department of Health and Rehabilitative Services.

Increasing attention was being focused not only on the need for better identification of SIDS cases and expanded research into the still unknown cause of SIDS but also on the need for better public and professional awareness of SIDS and the heavy burden of grief and guilt experienced by families of babies who die of this cause. Plans gradually evolved for a statewide program of education, identification and follow-up patterned along general lines of a program already in effect in Dade County (Miami). That program is based on cooperation between the Medical Examiner's Office and the Dade County Department of Health, with public health nurses following up on all infants with death found to be due to SIDS.

The state, therefore, was ready to submit a proposal when federal maternal and child health monies first became available in 1975 through the Department of Health, Education, and Welfare for SIDS information and counseling projects. The Division of Health's application was approved on July 1, 1975 to establish a program as previously described to include involvement of all concerned: general public, special groups such as medical examiners and other physicians, nurses and other health department personnel, social workers, mental health, law enforcement and emergency medical services personnel, and parents or parent groups. The principal objectives are to see that all Florida SIDS cases are properly investigated and identified, which requires autopsy, and that families are promptly notified of the cause and provided such counseling as they may require in the aftermath of bereavement.

The Florida grant included funds especially earmarked by HEW for a biregional SIDS Symposium for HEW Regions III and IV which include Alabama, Delaware, District of Columbia, Florida, Georgia, Kentucky, Maryland, Mississippi, North Carolina, Pennsylvania, South Carolina, Tennessee, Virginia, and West Virginia.

In compliance with this requirement, the Florida SIDS staff brought together in Atlanta on February 18-19, 1976 representatives of the six SIDS projects in the states of Alabama, Florida, Maryland, North Carolina, Pennsylvania, and Tennessee. Speakers of international prominence shared their expertise with persons working at the federal, state and local levels. The presentations are summarized on the following pages for the benefit of public, professionals and parents.

The Sudden Infant Death Syndrome
Current Knowledge

MARIE A. VALDES-DAPENA, M.D.
PHILADELPHIA

The definition of the Sudden Infant Death Syndrome agreed upon in 1969 at the 2nd International Conference on this subject is composed of two distinct and important parts: (1) clinically or by history it is the sudden and utterly unexpected death of a baby who appeared well or was only slightly ill, and (2) whose death remains unexplained after the performance of an adequate autopsy.

The phenomenon is worldwide. There are published reports from Russia, Japan, the Philippine Islands, France, Germany and Canada. Crib death does happen in the countries which are somewhat less sophisticated medically and in underdeveloped nations; however, their predominant public health problems in the realm of pediatrics are diarrhea, so-called marasmus and tuberculosis. Crib deaths do occur there but are hidden beneath the much larger and, for those people, more important serious diseases of infancy.

In the United States there are approximately 8,000 crib deaths each year. For us, then, this is a real public health problem. Cystic fibrosis of the pancreas, by contrast, claims the lives of 300 to 600 babies annually.

In 1971 Drs. Abraham B. Bergman and J. Bruce Beckwith of Seattle's Children's Orthopedic Hospital and Medical Center reported an incidence figure of 2.3 crib deaths per 1,000 live births in King County, Washington. Earlier data from Philadelphia showed 2.55, Cleveland 2.58, East Germany 2.6, and Belfast, Ireland 2.8. Canada has the highest figure at the moment, 3.0 per 1,000 live births.

In 1969 Dr. Beckwith, pathologist at the Children's Orthopedic Hospital and Medical Center, and Dr. Bergman using an incidence rate of 2.8 per 1,000 live births calculated the number of deaths which had probably occurred in each state of this nation in that one year. According to their calculations the approximated total sudden infant deaths were 9,999. Pennsylvania, for example, was thought to have had something over 500 such deaths and Florida, approximately 300.

Dr. Valdes-Dapena is pathologist at St. Christophers Hospital for Children in Philadelphia, Pa., Professor of Pathology and Professor in Pediatrics at Temple University School of Medicine, Philadelphia.

Regarding the relative importance of sudden infant death, in a series of 312 autopsies of babies one week to one year of age, Dr. Beckwith determined that 139 had died from Sudden Infant Death Syndrome. In other words, one can safely say that, in the first year of life, after the immediate neonatal period, this phenomenon accounts for something more than 1/3 of all postneonatal infant deaths. This puts the problem into perspective as far as its relative magnitude is concerned.

Characteristics of the Victim

One characteristic of the baby who is vulnerable to crib death is age; there is a definite peak incidence in deaths of this type between two and four months. Furthermore there is a kind of hiatus between birth and one and a half or two months of age during which time it does not appear to occur often. Experts believe this observation has significance with regard to the ultimate mechanism of death. What happens to babies that makes them most susceptible at three months when presumably they might be expected to be more fragile during the first month of life?

What has birth weight to do with it? The baby with an adequate weight at birth has a risk of only 0.87 per 1,000 live births. On the other hand, the baby of low weight or the premature has a risk at least six times greater, 6.55 per 1,000 live births. Prematurity or low birth weight appears to have some association with the syndrome.

If the baby is a single birth, his risk is only 1.46 per 1,000 live births whereas the risk for twins is 3.8 and for triplets 8.3. This, however, is probably nothing more than a reflection of prematurity and/or low birth weight.

Regarding the sex of the infant, in the realm of pediatrics, most serious diseases occur predominantly in the male. So, it is believed that there is no particular significance in this male preponderance.

Early in our investigations in Philadelphia, we discovered that we were seeing twice as many Black babies dying in this manner as whites. This was at a time when there were twice as many white children under five years of age in our city than there were Blacks, which means that the real or corrected rate for Black infants was four times greater than for whites. In California the risk for Oriental babies is 0.5, Mexican-Americans 1.7, other Caucasians 1.3, Blacks 2.9, and American Indians 5.9. Dr. Bergman reports that in King County the rate for white infants is 2.02, Blacks 4.8, and American Indians 8.58. In this country, then, the most vulnerable individual at this time would appear to be the American Indian infant.

It has also been established that the death rate is higher among Black infants than white no matter what the economic group; higher among the poor than among the rich no matter what the race. In summary, then, the baby most susceptible is one of low socioeconomic status in a minority group whatever that may happen to be and in whatever place. This is not an observation which has been made exclusively in the United States. Similar data have been reported from other countries as well including Great Britain and Germany.

What time of the year do most such deaths occur? It is rather solidly established that they occur in the winter time, or colder weather. In Philadelphia, for example, there is a tendency for such deaths to cluster in the late winter and early spring months — January, February, March and April — and to drop off in July, August and early September. This S-shaped curve of incidence is observed year after year. In Southern California and Seattle, however, where the climate is more temperate, investigators have not seen this striking variation in numbers of deaths with the summer-winter contrast. This demonstrates relationship to cold or at least suggests that upper respiratory or viral infections, so prevalent in cold weather, may play some role in the ultimate mechanism of death.

What about time of day? Most crib deaths occur between midnight and 9:00 a.m. Thus, investigators conclude that the syndrome is related, in all likelihood, to a protracted period of rather deep sleep. Furthermore, this is the first time in the baby's life, between two and four months of age, in which his mother permits him to "make it through the night" without the "two o'clock bottle." Physiologists tell us that our metabolic processes are basically different during deep sleep. Hence, something may well be altered in the rate or rhythm of respiration and/or cardiac function, or even body chemistry in the infant's long uninterrupted nighttime sleep and relative fasting. These issues are now being studied with regard to their role in the ultimate mechanism of crib death.

The total number of sudden infant deaths appear to be diminishing and so does the rate of its occurrence. One thing we have seen for certain in Philadelphia is that the number of all infant deaths involving infants under one year of age dying of any cause parallels the number of sudden infant deaths (1960 to 1974). The annual number of all infant deaths dropped from 1,400 to about 760 in that span of time and deaths from the Sudden Infant Death Syndrome from more than 100 to about 49. So, whatever, the phenomenon is we are seeing, its recent diminution in occurrence parallels that for all infant deaths.

There appears to be no correlation with the rate of illegitimacy

but there is a parallel in the reduction of inadequate prenatal care.

Possible Causes

The hypotheses as to why babies die suddenly and inexplicably are many. One concerns sudden changes in the rate and/or rhythm of the heart beat. However, there is no demonstrable morphologic or pathologic process, as far as the pathologist can determine microscopically, within the special nerve bundle of the heart which would explain a fatal dysrhythmia or arrhythmia.

Probably the most important hypothesis at the moment is that affected babies die because they suddenly stop breathing for a protracted period of time, usually while sleeping and most often when they have an upper respiratory infection. This theory was originally popularized by Dr. A. Steinschneider of Syracuse, N. Y. Not long ago, Dr. Richard L. Naeye at the Hershey Medical Center in Pennsylvania discovered morphologic evidence, which he could see microscopically, which tended to support the theory that the cause of death was spontaneous protracted apnea. His was an important observation for it was the first time anyone had been able to delineate any way in which these babies differed from normal babies. He observed that the walls of the small arteries in the lungs were measurably thicker than the walls of the arteries in the lungs of normal babies. A second observation was that these babies had abnormal retention of what is called "brown fat" around the adrenal glands. Our data to date support the observations of Dr. Naeye. At five months of age normal babies, on the average, have about 45% brown fat at this site; cyanotic babies have up to 90%. The figure for crib death babies is half way between the two. Brown fat of normal babies drops from birth to eight months of age. That in "blue babies" does not decrease so much while that in crib death babies on the whole is in between. Our data on more than 100 cases of crib death show that, as a group, affected infants do have relatively more brown fat around the adrenals than normal infants especially in the later stages of their development from five to eight months of age.

There is, however, a tremendous range for the relative amount of brown fat among both normal babies and crib death babies. Therefore, the pathologist cannot look under a microscope at an adrenal and its surrounding fat and state with certainty that this is a crib death because there is, for example, 60% retention of brown fat. This is not a diagnostic criterion. Pathologists do not possess any single criterion by means of which they can determine in a positive way that any given baby died of crib death. Nevertheless, there is something clearly and

demonstrably different about babies who die in this manner. They may retain their brown fat because they are chronically hypoxemic. This appears likely, at least.

In another study, Dr. Naeye demonstrated that the right heart of the affected infant is heavier than normal. He reasoned that if the affected baby lacks oxygen then the right heart must be working excessively to pump that relatively oxygen-poor blood through the circulatory system and one would expect that the overworked heart would have a thick-walled right ventricle. In a large series he did show that crib death babies have thicker walls for the right ventricle than normal babies.

In still another investigation, Dr. Naeye served as pathologist for a giant collaborative infant study designed to follow in detail the results of 50,000 conceptions. When a number of the 50,000 babies died from crib death, he asked the computer: How were these babies different from others who have remained alive and well? He found statistically significant differences of a functional or physiologic nature. They had, in general, lower Apgar scores when born, needed more resuscitation, had a lower birth weight, and more often needed gavage feeding. There was a tendency for them not to have a normal increase in weight in the first few months after birth. They were not very active, did not respond well to stimuli, had little tone, weak suck, and a more abnormal cry. Thus, it became evident that these babies had probably never been entirely normal, even in utero.

Conclusion

Great strides have been made in recent years regarding our understanding of sudden, unexpected and unexplained infant deaths. Although they would appear to be due to the sudden cessation of some fundamental physiologic process such as the control of heart rate or respiration, it is probable that the infants involved had not been entirely normal even during intrauterine life.

It appears likely now that the potential infant victim is susceptible from birth on and that sooner or later physicans will learn how to identify him and how to prevent his sudden death.

SIDS Parents Panel

Moderator

BARBARA BRUNER, M.D.

Panel Members

MRS. DONNA MUSSELWHITE
PHYLLIS BENJAMIN, R.N.
JERRY L. WINFREY

Dr. Bruner

My interest in the sudden infant death syndrome (SIDS) evolved through the years. I was in the private practice of pediatrics in Atlanta for 11 years and during that time one patient in my practice died of the syndrome at approximately four weeks of age. I remember my severe frustration and can appreciate the parents' difficulty because of the problem of getting the autopsy and of the fact that, though I was convinced it was this type death, the pathologist was quite adamant that the cause was suffocation due to vomiting. He found milk in the baby's mouth and upper trachea. The mother was unhappy with the final diagnosis and began searching for more information. More information became available in the pediatric literature and as you know the various SIDS chapters were organized throughout the country.

The local chapter in Atlanta was begun by one of our panel members, Mrs. Donna Musselwhite, along with other parents. Donna lost a baby and her response was to do something about it. She has become Southeastern Regional Director of the SIDS National Foundation.

Another panel member is Mrs. Phyllis Benjamin, nursing supervisor of ambulatory pediatric patients at Grady Memorial Hospital. This is a large charity hospital for the Fulton-DeKalb county area which serves close to 2 million people. As the city-county hospital we receive the majority of SIDS patients who are dead on arrival because of the necessity for the infants to be pronounced dead before they are sent to the medical examiner or coroner of the particular county of residence. Mrs. Benjamin and others of the hospital staff have an opportunity to talk with parents at the time they arrive at the hospital. She will give you her insight as a nurse who is one of the first in line in counseling the family.

Dr. Bruner is Associate Professor of Pediatrics at the Emory University School of Medicine, Atlanta.

The third panel member is Jerry Winfrey, senior accountant for the Metropolitan Atlanta Rapid Transit Authority. He and his wife lost a baby this past year.

Mrs. Musselwhite

I thought it would be beneficial if I dwell on what happened to us at the time of our child's death, both positive and negative. This is not the typical SIDS story but it is tragic enough.

From the time my child was put into the ambulance until we arrived at Metropolitan Hospital, everyone treated us with warmth, kindness and understanding. The ambulance attendants went to the emergency room immediately and I knew then our baby had died. I turned and said something like, "Oh, I guess there is something I need to sign." They were most solicitous and replied, "We can get every bit of information we need from the hospital." So, I chalk that one up to the positive column.

Fortunately, our pediatrician was in the emergency room. He came out after examining the baby and the tears rolling down his cheeks not only showed his concern but confirmed what I already knew. My husband arrived and we sat down and talked with him. On the negative side, he did not recommend that we have an autopsy. On the contrary he said there was little or nothing an autopsy would reveal, that he knew it was a classical sudden infant death syndrome and proceeded to tell us what few facts he knew at that time. He knows a lot more now because I have bombarded him with literature. Still he is yet reluctant to recommend an autopsy.

It was but two weeks before I began wondering: what is a crib death? why me? what if it was something else? We have regretted that we did not have an autopsy done, even though I wanted to believe it was not my fault and not feel guilty. An autopsy report is something concrete in black and white.

It is comforting to go back in time to the hospital during the period we were waiting to handle the paperwork and other details. There was a student nurse in the emergency room and I have tried to locate her. I thought she was doing for me what every family received in the emergency room. I know now that this is not so. She sat with us, talked to us, told us about an organization parents might belong to. There was no chapter in Atlanta. She wanted to know if there was someone she could call, if there was anything she could do for us. The time when we needed just to sit in silence and cry, she was there not saying anything.

It is not all times that emergency rooms are quiet enough for nurses

a tear or two does not make us any less a competent nurse.

We know that parents are in shock and try not to give extensive information on sudden infants deaths. We do feel that a few objectives should be met before they leave us in order that they may continue with the agencies we refer them to. We communicate to the parents that SIDS is a disease that no one can prevent. If parents are accompanied by policemen, neighbors or other persons, we make an effort to inform them about the disease and the need for compassion and understanding. We establish with the parents the knowledge that an autopsy will determine the cause of their child's death. There is more we can say and do for these families.

Mr. Winfrey

Last week when I was asked to speak I began trying to put my thoughts and feelings into words and found it impossible. The tragedy of losing a baby is too personal. The story brings back pain and sorrow that's still with me and appears will be for some time.

On June 5, 1975 I called my two boys at home to tell them they had a baby sister. To say I was overjoyed and filled with pride would be an understatement. I felt relief that our third child had been born healthy, was doing fine, and recall the first time the nurse brought her screaming into my wife's room. She said, "Daddy, you had better get used to this again," and placed her in my arms. My daughter quit crying immediately, and she then became daddy's girl.

My wife and I took her home and she continued to be a good baby, slept through the night and awoke each morning alert, wide awake. She cried little, ate well, and appeared healthy. On July 10, my 31st birthday, she was taken to the doctor for her fifth week check-up and he said she was thriving, the perfect example of a healthy child.

My daughter died two days later during her afternoon nap without warning or symptoms of illness. I was working 25 miles away when a friend and a police officer came for me. The officer, who also serves as a voluntary chaplain, made the ride home the longest I have ever had. He repeated over and over that our daughter had died of pneumonia. I could not understand, believe nor accept it for I knew the care she had received. There is no way we could have overlooked a temperature, signs of congestion, or cries of pain.

Our daughter was pronounced dead at home. When the rescue squad took her they advised my wife not to accompany them, left her at home with friends. When I got there we did not know where our child had been taken, assumed it to be DeKalb General Hospital since it was the closest one. We were unable to get in touch with our

doctor. He was off duty that Saturday and the doctor taking his calls, for some reason, did not consider it important enough to find Him and tell him one of his patients had died. He did not learn that our baby had died until Monday afternoon. This was the least of our problems.

When the coroner called that night to tell us our daughter had died of sudden infant death syndrome, we assumed that an autopsy had been performed, how else could the cause have been determined. But it had not been, a fact we discovered when we went to see our doctor the day after the funeral. After looking at Jessica's medical records and asking us extensive questions regarding her condition and actions before death, he agreed with the coroner and medical examiner

These past seven months my wife and I have realized that our story cannot end until every state requires an autopsy on all these babies. It should be mandatory because during this time of grief parents may not be capable of making the decision. It should be made for them and paid for by the state or federal government.

We believe that professional counseling is needed after the tragedy, not during it. Friends, family and neighbors pull you through the immediate crisis but those long months after, when everyone is hesitant to discuss the tragedy, is the time when you need someone.

The parent contact program is great and should be continued, either in an organized or spontaneous manner. To know that someone has gone through what you have, to know that they are there to listen, can and does help even though the stories and circumstances are different.

We need a reason why our daughter died and this means extensive research. Someone has to decide that enough children have died and it is now time for an all-out campaign to eliminate the cause, not just explain it to us so that we will understand.

Dr. Bruner

A few things have become obvious to me in talking with parents at the time the children are brought to the hospital and then following up after the autopsy. Generally the human population has a habit of jumping on bandwagons. Whatever the prevailing subject comes in for a great deal of comment and interest. SIDS is fortunate in that people are becoming more aware of it. There is more research and more money coming from different sources.

As both our parents have commented we have a lot to learn. We are finding that pathologists, who, as a rule, abhor the conclusion that they really do not know why the child died, are accepting SIDS more or less. They say, "SIDS," without always realizing that part of the

definition, as Dr. Valdes-Dapena mentioned, is the necessary comment that the death is unexplained by an adequate autopsy. We are finding that medical examiners certify SIDS without going through an autopsy and that coroners are willing to accept the diagnosis without expending finances to fund the autopsy.

Few parents can afford an autopsy which is estimated to cost from $250 to $400. Few families in the emotional crisis of death think of alternate means of getting one performed if the local official refuses to do it. I am pleading perhaps not for mandatory laws saying it must be done but that it should be done and for something more than just looking at the body or listening to the story over the telephone and saying, "Oh, SIDS."

Dealing with the family at the time is made somewhat more difficult when we obviously can no longer say, "Yes, your baby will be autopsied." We can only speak from our experiences that the details are compatible with SIDS. I have had the same concern as Mr. Winfrey in assuming an infant had been autopsied only to find some days or weeks later that it was what the medical examiner called a postmortem. To me that is the equivalent of an autopsy but I find in legal terminology that postmortem is looking at the outside of the body and an autopsy is looking at the inside.

The afternoon nap.

Grief Counseling

North Carolina SIDS Project Approach

RUTH ANN YAUGER, R.N., M.P.H.
CHAPEL HILL, N.C.

The Sudden Infant Death Syndrome Project in North Carolina has been labeled unique by authorities in the field. Future events and final results will determine its value to the families involved. Similar to most SIDS projects, it is primarily concerned with providing services, but it also collects data and disseminates information. Prior to federal funding counseling and collection activities were performed by one person with some financial support from the Office of Chief Medical Examiner, Division of Health Services, Department of Human Resources.

Concerns include the relatively unstudied status of SIDS families, particularly the level of functioning to the crisis; lack of information in the bereavement literature about the import of the sudden, unexpected loss of an apparently healthy baby on a young family, and the generally accepted statement that "all SIDS families need counseling." This led to some difficult questions, such as: without information about the population at risk, particularly antecedents and outcomes, how can counseling be appropriately structured and evaluated? Without an answer to the first question, how can the provision of counseling be justified with any degree of rationale?

Commitment of the North Carolina project to provide services and at the same time collect data for preliminary answers as well as function with limited resources at its inception help to explain its approach.

Counseling Activities

Gerard Egan in "The Skilled Helper" states that "counseling is not a neutral process; it is for better or for worse. Unsound counseling (intervention) can interfere with the healing process, or grief work." My opinion is that grief counseling is similar to other kinds of counseling. The counselor must be at ease with himself as a helping person, comfortable with the confronting and confounding problems, and capable of being directive or indirective as the situation warrants.

A critical element in grief counseling, aside from the psychological tone of the helping climate (or relationship), is assessment of the

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individual's position at various times following the crisis. Position is defined as a point along a continuum, including past and present life experiences and influences, as well as distances from future goals. We visit and "assess" families three times. Time I is at three to five weeks, Time II at seven to nine weeks and Time III at four to six months.

Although data collection questions were not designed originally for use in counseling, they do provide opportunity for discussion of issues and feelings. Families have remarked to nurse-counselors that answering the questions makes it easier to talk about events that no one has let them discuss. The style of questioning is relaxed and informal; the words used are short and easily understood by the tri-racial families.

At Time I the major emphasis is on SIDS as a disease and the normal signs and symptoms of grief or bereavement. If feasible, and it almost always is, data are collected about sociodemographic variables, case management, significant life events prior to the crisis, bereavement behavior, and SIDS etiology. Questions enable parents to tell what happened right after they found the baby and encourage them to describe the baby's life in detail with special emphasis upon the last week and last several hours of life. This also provides the nurse-counselor with useful clues concerning the parent's grief rationale.

Data collection at Time II is directed at social supports including religion and notions about death, bereavement behavior, and outcomes. Counseling is focused upon pertinent issues as well as current concerns.

At Time III only bereavement behavior and outcomes are assessed. Counseling is present and future oriented. If maladaptive outcomes are identified, these and possible action/corrective strategies are discussed. If necessary, referrals are initiated at any time during work with the families; however, very few have needed this help.

Bereavement Behavior and Outcomes

Measurement of bereavement behavior at all home visits is relevant to the subject of grief counseling and is used to assess progress of the mother through the stages of acute grief. It is usual for her to answer the questions, then stop and recall how she answered the time before, thus ascertaining her progress. The fact that the questions were asked at Time I seems to reassure many mothers. Sometime the symptoms of normal grief are not known.

The questions deal with sadness, loss of appetite, sleeping problems, increased irritability, problem in returning to usual activities, and preoccupation with thoughts and memories about the baby.

A mother who had lost her first daughter to SIDS five months

previously remarked to me after answering the questions regarding bereavement outcome that they helped her to tell me just how badly she was still feeling. She had been unable to verbalize to her physician, who was a good friend, during a conference several days earlier. She gave me permission to share her scores which were suicidal level with the physician and an appointment was arranged within hours.

Conclusion

The combination of counseling with data collection may appear distasteful but the procedure appears to have been highly acceptable to families in North Carolina which have lost an infant to the Sudden Infant Death Syndrome. The reasons may be a carefully structured interview designed specifically for families and their special needs, rigorously pretested and modified, and carefully and caringly administered by four nurse-counselors.

Counseling is crisis oriented. It is brief, active, goal oriented, and concerned with present adaptation. Some might call it no more than structured psychosocial interaction; however, families tell us that we are helping in ways no other person has. The nurse-counselors' roles include that of teacher, supporter, and advocate. Major functions are reality emphasis, assessment, enhancing use of situational supports, helping to redefine life without the child, and providing emotional support.

It is possible that the current special programs of grief counseling could be expanded to include other high risk populations such as accident survivors. First, however, it must be demonstrated that grief counseling "makes a difference."

Waking up — and no one is there.

Medical Examiner's Relationship With SIDS Parent Groups

JOHN J. SHINNER, M.D.
LARGO

Until three years ago I had knowledge of the sudden infant death syndrome as a pathologist but was unaware of its implications upon the family. As a physician this was an important lack in my experience. Other pathologists and medical examiners may have a similar situation. The reason for this presentation is to suggest means by which this problem may be partially solved and more cooperation be brought about between medical investigative services and the local community.

It would be worthwhile to define terms. The pathologist is a physician, a specialist just as the surgeon, psychiatrist, internist or pediatrician would be. His field also is known as laboratory medicine. Through training and experience he becomes familiar with the naked eye or gross appearance as well as the microscopic appearance of the effect of disease upon the patient. Since forensic connotes legal implications, the forensic pathologist then would be involved in court cases. His wide-ranging interests are directed largely toward recognition and study of the effects of various trauma or injury upon the patient and he seeks to distinguish these from the effects of disease processes.

An autopsy is an examination, a tool for a specific purpose; namely, to solve a problem which often is mundane or of an every day nature. The performance of an autopsy by a medical examiner is an absolute necessity in certain instances.

The coroner is an individual, not always a physician, charged with the responsibility for investigating certain kinds of deaths, for instance, the sudden and unexpected death in an otherwise healthy individual. He may be a judge or lawyer and, therefore, has the authority, training and skill to obtain evidence under oath at an inquest.

The medical examiner is a physician, often a pathologist. Because he has not been trained in law, he cannot properly come to a rational legal conclusion about why a person died but he does understand the medical problem.

There is some misunderstanding about the importance of the medical examiner's cooperation in sudden infant deaths. The need for his assistance is very real for individual cases are significant and rep-

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resent a problem that must be solved.

In 1972 Dr. Abraham B. Bergman of Seattle randomly selected on a statistically valid basis 148 communities throughout the United States and studied each rather carefully from the standpoint of how the SIDS problem was being handled. Pinellas was among the counties. The study indicated that cause of death of these babies was being certified by coroners 42%, medical examiners 31%, and miscellaneous 27%, which included persons not really qualified to make this decision. In 29% of the communities 100% of these babies had an autopsy and in 20% one out of every five. In 10% of the communities the family was billed for the procedure and in one third nonpathologists conducted the examination.

Two brief case histories illustrate the problem.

The mother discovered her two-week-old baby lifeless in bed with she and her husband. The body was taken directly to the funeral home which was owned by the coroner. He told them that some parents kill their children but he did not think they had done so. They were not encouraged to have an autopsy on the baby. The local physician told them that pneumonia probably killed the child but on the death certificate "probable asphyxiation" was noted. This diagnosis with no other explanation may be unnecessarily upsetting.

A Black woman with many children found her baby lifeless in bed one morning. She thought the child had suffocated. The police were called and the child was taken to the funeral home. There was no autopsy but the mother was sophisticated enough to want to know the cause of death. She has never seen the certificate. Her obstetrician told her the child had a heart defect and would have died at about 12 years of age.

How is the medical examiner important in these cases and to groups with special interests in the cause and possible prevention?

The medical examiner is notified of these deaths within a very short time of their discovery and is a reliable source of names and addresses of people who should be contacted. He has quick contact with other groups in the community, with family doctors and pediatricians, the local medical society, police department, clergy, funeral directors, and emergency medical service groups. There is a great deal of interest in current research regarding prevention; the medical examiner can contribute significantly.

When the medical examiner is approached for assistance, it should be done with proper credentials because the question arises in his mind as to the reason he is being requested to become involved. It is important to be able to tell him. Like other physicians he is busy

but he will cooperate when provided with sufficient reason.

The National Association of Medical Examiners encourages its members to become involved in SIDS cases with these statements:

"that members of the Association be available to explain the known phenomena of this syndrome to parents, physicians, government officials and citizens at large, and that prompt notification of families as soon as possible after confirmation of a diagnosis is desirable."

"that this Association recognizes that good can be derived from all voluntary citizens groups and that such organizations have a beneficial role to play in both interaction with parents and other family members, as well as assisting in the discovery of the cause and prevention of this syndrome."

"that the Association, whose goals include the necessity of proper certification of death, emphasize the importance of the autopsy in cases of sudden, unexpected infant death, and strive to standardize death certificate terminology utilizing nomenclature in The International Classification of Diseases. For those cases falling within this category, (when no cause of death could be determined), Sudden Infant Death Syndrome, S.I.D.S. appears to be an optimal term."

Feeding time.

Role of Public Health in SIDS Case Management

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ATLANTA

Public health has a definite role in meeting the needs of parents who have lost a baby to the sudden infant death syndrome (SIDS). It is a good sign that emphasis is being given to this role not only in case management but in education and awareness. Health personnel must meet the challenge and respond to the need.

I would like to discuss three areas where public health can and should assume some responsibility: (1) provide support to parents, (2) promote public awareness, and (3) improve reporting of SIDS and encourage the medical examiner to more accurately determine cause of death.

Parent Support

Almost all parents who have experienced the loss of an infant by SIDS need the opportunity to share with some understanding person what they are going through. In many communities the public health nurse may be the most appropriate person for this especially if the physician is not available or appears to prefer that someone else "deal" with the family. Public health nurses usually know most of the people in the community and are familiar with a wide range of available resources. The nurse is well trained to listen and share information. In many localities she makes home visits and appreciates and responds to the needs of all members of the family, since most public health nurses are accustomed to providing services for the entire family. Not only do parents need the opportunity to discuss their feelings, ask questions and share their experience relating to the death of the child, but also the siblings in the home need to be supported. At such a time many parents find it difficult to relate to their other children and answer their questions when they themselves are seeking answers.

To be effective, such a visit to the family should be within a few weeks of the death of the infant. It should be as relaxed as possible, informal and friendly. Adequate time should be allotted, 45 minutes to an hour. Repeat visits may be indicated and necessary depending upon the individual family. It will also help for the nurse to leave her

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name and telephone number to allow the family to get in touch with her if necessary. During the initial visit it is important to let the parents tell what happened — recall how the baby was found, how the infant was prior to the event, what they know about crib deaths or the sudden infant death syndrome. Do both parents understand or is one unwilling to accept the diagnosis and, therefore, likely to blame the other for what was done or not done? By talking with the parents, their feelings will be expressed as to guilt, blame and fear. This allows the nurse to reassure them as appears desirable.

The nurse can be a real help when through lack of understanding parents are being accused of contributing to the child's death through neglect or abuse.

It is unbelievable how some parents have been held for manslaughter and dealt with "inhumanly" by authorities. The public health nurse may well be the one who, expecially if she has known the family and has previous contact with them, can best give the support needed.

Mention must be made of training which nurses will need. It is important to stress that public health nurses need to be well informed about SIDS and aware of new findings relating to crib death if they are to perform their role. This is extremely necessary if the nurse is to be able to answer adequately the many questions which parents may ask. I feel nurses will and can learn much from these contacts with parents.

Abraham B. Bergman, M.D., Associate Professor of Pediatric and Health Services at the University of Washington, writes in the February 1974 issue of Pediatric Clinics of North America:

"Because of the inverse relationship between sudden infant death syndrome and socioeconomic class, a disproportionate number of families lack any personal physician and thus tend to suffer the worst consequences. In other words, the less educated families who have the least information about sudden infant death syndrome and are least likely to get sympathetic treatment from 'the system' are the very ones who will benefit most from a supportive physician at their side. Alas, the world does not work that way. An appropriate alternative, however, is utilization of specially trained public health nurses to provide information and counseling to all families who lose babies to sudden infant death syndrome. The training required is not elaborate; it involves learning some basic facts about sudden infant death syndrome and the attendant grief reactions."

It was of interest to me that in this same article Dr. Bergman relates the experience of a pediatrician who lost her baby to SIDS. She had a severe grief-guilt reaction which was alleviated only after being

treated as a grieving mother. All her knowledge of research of SIDS was unable to give her the support she needed which was that of a warm understanding friend.

Public Awareness

A second area where public health can exert tremendous influence is in education and awareness. Local health departments are known for their ability to provide information to the public on a wide range of health related matters. Many health departments have in the past conducted discussion groups, presented audiovisual materials, made pamphlets available and even used the news media to increase awareness of health problems and needs of the community.

Some health departments are fortunate enough to have a staff of health workers which may include such personnel as a health educator. The dispensing of health information is more often the shared responsibility of many members of the staff.

The following quote from a parent who had been charged with involuntary manslaughter expresses the need for more public understanding and information: "The death of a child is bad enough. It is the harassment and lack of knowledge, lack of understanding and lack of compassion that hurts more than anything else."

One area in which SIDS chapters have been most effective has been in the area of increasing the public awareness — not only public but parents, officials and, yes, even the professionals. I see this need to be extremely great — time, money and energy put toward improving understanding and awareness of crib death may be as important and rewarding as any activity we can undertake.

Improved Reporting

Public health should play a role concerning the need for improved reporting, more accurate determination of the cause of death. It is well known that many crib deaths are not listed on death certificates as SIDS. This makes it impossible to know the magnitude of the problem. Physicians and others should be better informed as to the accepted terminology — and should use it. Physicians should list such deaths on the certificate. This is a shared responsibility with the health department and physicians.

Closely related to the importance of uniform reporting on the death certificate is the need for more accurate determination of the cause of death. This may mean that autopsies should be performed by adequately trained pathologists. It has been suggested that regional centers for such service may need to be developed. Improved reporting and

autopsy services are listed in the four point program of the SIDS National Foundation.

State health departments are in a position to give support; however, as is so well known funding is a very crucial issue especially at this time.

King County in the state of Washington has become a model community in its method of handling SIDS cases. Each victim is automatically autopsied and the findings immediately reported to the family. A public health nurse maintains contact with the family for an extended period to offer counseling and answers whatever questions that may arise.

Let us all work toward that time when this will be the practice in most communities. It may not come next year or the next, but we can and should work and plan for such a time in the future.

Strolling with mother (and crying).

Role of First Contact Personnel in SIDS Case Management

Leo C. Lefebvre Jr.
Philadelphia

First contact personnel are considered those persons who come into contact with the family within 24 hours after discovery of the infant who has died due to the sudden infant death syndrome (SIDS). These may include police and other law enforcement officers, rescue squad, emergency medical technicians, hospital emergency room staff, medical examiner investigators, nurses, social workers, clergymen, pathologists, funeral director, pediatrician, and neighbors.

Two critical areas need particular attention: police or law enforcement officer and hospital emergency room staff.

Law Enforcement Officer

The police or law enforcement officer has a job to do and must perform his duty in a relatively short time. He has a responsibility to the infant as a protector of life; to the family as a leader during a crisis, and to society as an objective observer and investigator. There is no reason, however, why he should be anything but constructive in dealing with the sudden death of an infant when apparent evidence indicates death due to natural causes. He can help to relieve the immediate gult and anguish of the family or reinforce guilt that may have life-long implications.

If the officer is unaware of the sudden infant death syndrome, the tendency is strong to make a wrong assumption. He should know that SIDS occurs among infants between one month and one year of age who are otherwise apparently healthy and while the infant is sleeping. He should be able to recognize the formal, routine signs surrounding the death: a small amount of blood-tinged fluid in and around the nose and mouth, bruise-like marks on the body where the blood settled after death, and rumpled covers or the head face down in the bed clothes.

The officer should know that the parents experience severe psychological reactions to the death in the form of shock, grief and guilt. The parents' reactions are individual and a variety are normal. They may be emotionally convinced they killed their baby. They may be

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glassy-eyed, tearless, dazed; appear vague and confused, give an inconsistent account with evasive answers; hysterical, incoherent, unable to recall clearly what happened.

When the officer recognizes a potential sudden infant death, he should be prepared to relieve the immediate anguish. He can delay criminal investigation until after the autopsy, conduct his investigation in a patient, sympathetic manner and his interview with dialogue not an interrogation. His questions can be positive and not asked in a manner which reinforces the already-present self-inflicted guilt of the parents.

These questions should not be asked at this time: Have you ever hit the baby? Have you dropped the baby recently? Have the other children climbed into the crib? Have you or any member of the family been ill lately?

These questions should be asked: What happened? How would you describe the baby's health? Were there signs of illness? Who found the baby?

It is the duty of professional persons in various disciplines to provide the law enforcement officer with the proper training so that he feels comfortable in dealing with SIDS cases. He must have a plan of action he feels at ease implementing. He can begin to feel comfortable if he is informed about the disease entity and learns to deal with his own reactions to it before reaching out in a constructive manner to families.

Hospital Emergency Room Staff

The hospital emergency room staff should have a plan of action for dealing with SIDS cases. These persons, nurses, aides, technicians, orderlies, should recognize a potential case and then initiate the plan for professional and humane family care. The patient, of course, is first in their consideration.

There are five critical categories.

First, the apparently lifeless infant is brought to the emergency room. The evaluation is made by the physician with nurses assisting whether to begin resuscitation measures. At this time a member of the emergency room team should be assigned to stay with the parents. A private area is necessary so that she can obtain an accurate history as well as an account of recent events. She should contact any parent who is not present or other persons whose presence appears essential to the parents' well-being.

Second, if death occurs the team reviews all information and determines the appropriate and sensitive approach to the family. The sudden

infant death syndrome should be considered as a probable cause of death but only as a tentative diagnosis when the infant is under one year of age, there is no apparent injury and no illness other than possible mild upper respiratory infection.

Third, the physician with the emergency room staff member assigned to the family should inform the family of the death. The physician explains the legal requirements for an autopsy and can minimize anxieties by equating the procedure to an operation performed carefully and respectfully. Also, the physician explains that the examination rules out injury, unsuspected congenital anomaly or illness as a cause of death. This might not seem important to parents at the time. When the next pregnancy is considered, however, this information becomes critical to their emotional well-being. The physician also should contact the family's physician and inquire if they have other questions or problems.

Fourth, the parents should be given an opportunity to see the baby. This is carried out privately with only the emergency room person present to answer any questions and provide moral support. Parents who take advantage of the opportunity not only are able to say their goodbys but also to focus on the reality of the death. The parents may not be familiar with funeral arrangements and at this time it may be helpful for someone to inform them of the need to contact a clergyman and a funeral director.

Fifth, because of the shortness in time and emotional impact involved, it is important that the emergency room staff actively recognize the personal stress involved in the situation. Just as parents are offered support, the staff needs to support one another.

Other Personnel

Rescue squads and emergency medical technicians need to be presented with facts about the sudden infant death syndrome along with characteristics of the appearance of normal death. They need specialized training in the emergency care and resuscitation of infants and basically need to know how to relate to parents in crisis situations.

The funeral director should be aware of the special needs of parents and family. He can determine these needs by offering constructive suggestions such as "If you would like I can arrange for you and your wife to be with the baby before we go to the cemetery," or "Do you have something special you would like to include in the service?" or just "Do you have any questions?"

The medical examiner investigator needs to obtain his information in dialogue rather than interrogation. Basic SIDS facts will help to in-

crease this sensitivity.

The pathologist needs background information that is accurate and descriptive of the family and the circumstances surrounding the death of the baby. This allows him to interface with the family on a more personal level. He should be provided with follow-up reports on individual cases since he is likely to have a keen interest in the family's welfare.

Neighbors can be supportive if they are aware of SIDS, or they can be cruel and isolating.

Community nurses can perform the required follow-up if other previous experiences with the family have been positive. It is the job of the nurse to assess the family, then proceed with a plan to put them back in touch with each other and to reestablish them among their immediate community supports. The nurse needs to be provided with additional education in death and grief counseling and in assessment techniques. She must have resolved her own feelings about death and be comfortable with them before she can be effective with the family.

Physicians need to be more active in their relationships with the parents and available for counseling. They should play a major role in management of the case. Some have been difficult to reach and have presented misleading advice in an attempt to provide a diagnosis.

Conclusion

First contact personnel need to be knowledgeable about the sudden infant death syndrome, to recognize that the problem includes parents, siblings, neighbors, babysitters and relatives, and to be part of a team that communicates. Police and law enforcement officers have information to offer the emergency room staff. The staff needs to provide feedback to the police. The coroner and medical examiner need to link up with the public health nurse. Parents need attention from the pediatrician who must have a full report.

First contact personnel need to be prepared to cope with parents in severe distress. Each community needs a follow-up plan which insures parents the option of counseling.

Acknowledgments

This issue of Florida's Health and the biregional symposium from which the presentations contained herein were drawn resulted from the efforts of many people who seek the answer to a very perplexing public health problem.

Florida's Sudden Infant Death Syndrome (SIDS) Information and Counseling Project grew out of the interests and concerns of James E. Fulghum, M.D., Chief of the Bureau of Adult Health and Chronic Diseases and Emily H. Gates, M.D., Administrator of the Child Health Section, Health Program Office. Drs. Fulghum and Gates, initial co-directors, provided the guidance and direction in development of the Project's programmatic thrust.

Upon retirement of Dr. Fulghum in December 1975, James A. Hinson, III, M.P.H., Health Program Specialist with the Bureau of Adult Health and Chronic Disease, was designated Project codirector with Dr. Gates. Mr. Hinson had been serving as Acting Project Coordinator.

Dr. Gates and Mr. Hinson have shared in the overall administration of the Project, presentation of the symposium in Atlanta and in preparation of the material included in this issue of Florida's Health.

Assistance Available

Questions or other requests for information about SIDS may be directed to the Sudden Infant Death Information and Counseling Project, Department of Health and Rehabilitative Service, Health Program Office, P. O. Box 210, Jacksonville 32201, telephone 904/354-3961, extensions 343 and 445; National Sudden Infant Death Syndrome Foundation, Inc., 1501 Broadway, New York, 10036, telephone 212/563-4630, and International Guild for Infant Survival, 7501 Liberty Road, Baltimore, Md. 21207.

Limited quantities of several pamphlets are available upon request. Also available on loan is the film, "After Our Baby Died." The pamphlets include "The Sudden Infant Death Syndrome," DHEW publication no. (HSA) 75-5137, for use with professionals involved in various aspects of SIDS work; "Facts About Sudden Infant Death Syndrome," National Sudden Infant Death Syndrome Foundation, New York, N.Y., for use with general audiences; "After Our Baby Died," guides for 16 mm movie by same title, DHEW publication no. (HSA) 75-5126A, for use with general audience.

Materials on specialized subjects with reference to SIDS including funeral directors, law enforcement officers, emergency medical service personnel and others are available upon request from the Florida SIDS Project.

to take that time from their work, but some warmth is essential. Certain things are comforting and probably the first is knowing that someone does care.

I contacted the funeral director, our family and grandparents who were all most supportive, most understanding. None said, "Crib death? I've never heard of that, I don't believe it," or "I never did think she was a good mother."

About ten days after the baby's death, a policeman came to the door and said, "Don't be alarmed; this is a routine investigation. Anyone who dies in this county and is not attended by a physician we have to visit." He came in and I told him what had happened, what our physician had said.

"Well," he said, "I've heard of that; it's very strange."

He was very serious but not the least comforting but he was not irritating by any means either.

I kept thinking, "Well, this is his job and he has to do it."

As he was getting up to leave, he said, "Well, you know, this is a rural county and we see a lot of these cases."

"Oh, really," I answered.

"Yeah, but most of them are black babies and well, you know, they just seem grateful that the child died."

And that was what planted the seed in my mind that something had to be done. I felt right then that I had been fortunate. It was the beginning of my realization that other families were not.

Mrs. Benjamin

"There is little one can say and little one can do except express the heartfelt wish that God will comfort you." These lines remind me of the frustration and helplessness my nurses experienced in the emergency room when a sudden infant death happened. It was obvious that the baby was well cared for and that the parents were good parents. I am afraid we left the impression and the feeling that "This is your problem." We had no way to cope with our frustrations. Sudden infant death came to us often and caused us to realize that grief-stricken parents were victims of our frustrations. In some cases very little empathy was attempted.

At this time we do not know what causes these deaths but thanks to research and concern for humankind we do have a handle to work with. We have some facts and can extend emotional support. We recognize the parents' frustrations and accept them irregardless of how they express themselves. We sense the need for warmth and concern, a gentle hand, box of Kleenex and privacy. We also found out that